



Family-Centered Care Meeting the Needs of Patients' Families and Helping Families Adapt to Critical Illness

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PRIME POINTS

- Family members of patients in ICUs may experience fear, anxiety, depression, and posttraumatic stress.
- Nurses and physicians do not accurately predict the needs of patients' families.
- Individualized instruction, with proactive assessment of family needs in a manner that promotes the inclusion of patients' family members in bedside care, may help fulfill the needs of patients' families and optimize family members' adaptation to critical illness.

Anniversary

*She shuffled into my office
eyes deadened from 365 sleepless nights,
more than lonely, lost
since he's been gone.
It is time. She'll have her answer.*

*"Why did he die with a hole in his chest?"
she asks with a firm frail voice found
after the self-imposed
ascetic silence of grief.
Surely he should still be here.*

*Hole? Hole . . . enigmatic hole . . .
Visions scintillate. Final moments.
Last breaths.
The image is conjured and crystallizes
of a far less than fatal, failed attempt
at a line insertion.*

*If only. If only she'd come then,
or we had thought to ask.
Her heart, an empty vessel of mourning
would ache, but the tortured anguish
of the unanswered question
never needed to be.*

This poem is based on a true experience that I had with an elderly woman when I was working as a nurse manager/clinical nurse specialist. The woman experienced unnecessary

distress after her husband's death because she lacked information about the cause of death and had misinterpreted events. She carried this burden for a whole year before getting clarification. The vignette illuminates a common problem in the intensive care unit (ICU). Patients' family members are personally affected by the experience with critical care. Each family member's own health and well-being may be affected by whether his or her needs are met and by the actions of the health care team.^{1,7}

Effects of Critical Illness on Patients' Families

In the terms of the grand theorist, Sister Calista Roy, critical illness

Continuing Education

This article has been designated for CE credit. A closed-book, multiple-choice examination follows this article, which tests your knowledge of the following objectives:

1. Identify 3 adverse psychological outcomes of family members of patients in ICUs
2. List the 5 categories of needs of the Critical Care Family Needs Inventory
3. Examine methods of assisting families in reflective inquiry and family inclusion in care

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causes a disruption in life.⁸ The disruption requires a period of adjustment called the compensatory process that results in adaptation to the event. Adaptation can be positive or negative, complete or incomplete, depending on what happens during the adjustment period. The process repeats itself, and as a patient's condition changes, the patient's family must adapt to these changes. For the widow represented in "Anniversary," her husband's caregivers did not provide her with the information that would have decreased her distress. The lack of a timely debriefing to clarify misconceptions led, in this case, to a maladaptation to bereavement. The impetus for writing this article came from work on a project to synthesize the family support literature to create a guideline for family support in the patient-centered ICU⁹ for the American College of Critical Care Medicine and the Society of Critical Care Medicine. That guideline includes a section titled "Family Coping" that briefly summarizes how patients' families adapt to critical illness. The summary concludes with recommendations to provide patients' families with timely, accurate, and consistent information in an attempt to optimize the families' experience.

In this article on family adaptation to critical illness, I review the results of descriptive studies related to needs of patients' families, studies

on the relationship between meeting family needs and adverse psychological outcomes, and studies intended to help define nursing interventions to meet the needs of patients' families.^{1-3,10-13} The level of current evidence guiding practice is defined according to the GRADE (grading of recommendations, assessment, development, and evaluation) system.¹⁴ The GRADE system has 4 levels of evidence: high, unlikely further research would change findings; moderate, some likelihood further research may change findings; low, very likely further research may change findings; and very low, evidence is not strong enough to truly estimate effect of intervention at this time.

Descriptive Studies

In a qualitative study by Titler et al,¹⁵ patients' family members reported that the ICU experience was an overriding threat characterized by vulnerability, intense emotion, fear, and anxiety. In addition, the experience caused a disruption and changed intrafamily relationships, resulting in role strain. Titler et al concluded that nurses should test interventions that are geared toward conveying information between a patient's nurse and the patient's family.

Several studies have focused on the need for information and communication. In another qualitative

study, Nelson et al¹⁶ found that families of patients who required long-term mechanical ventilation and tracheostomy valued receiving information on the illness and treatment, what would happen in the future, treatment burden, potential complications, what to expect after hospitalization, and alternatives to treatment. The results of 3 surveys¹⁷⁻¹⁹ of bereaved relatives of ICU patients suggest a relationship between perceived effectiveness of communication, proximity to the patient, and satisfaction with care. In a multidisciplinary study by Cuthbertson et al¹⁸ on family needs, the largest volume of complaints offered by patients' families were related to restricted access and poor communication. Satisfaction of patients' families was inversely proportional to the number of attending physicians involved in the case. Satisfaction also decreased as the number of nurses who cared for a patient increased. Cuthbertson et al concluded that consistency in communication was a key to the satisfaction of patients' families.

In a survey by Abbott et al,¹⁹ 48% of respondents reported family conflict during the ICU experience and indicated that this conflict was caused by ineffective or inappropriate communication by the health care team. Family members frequently reported the need to know more information but never reported that too much information was given. That study setting had an open visiting policy, and the survey respondents commented on how much they appreciated the unrestricted access. In another survey,¹⁷ 17% of respondents thought that they had received unclear information or not enough information. These studies indicate

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that the needs of patients' families for information and proximity are commonly left unmet.

The importance of information and proximity are further supported by the group of studies in which the Critical Care Family Needs Inventory (CCFNI)²⁰ was used.

The CCFNI has 5 categories of needs: support, comfort, information, proximity to the patient, and assurance.²⁰ In an analysis of 18 studies in which the CCFNI was used, Leske²¹ found the tool valid and reliable in its complete form. Although all needs on the CCFNI may not be important,²² informational needs are the most important²³⁻²⁷ and are often unmet.²⁸ Recently, a group of physicians in

values, which may not accurately reflect the actual needs of a patient's family.³⁰ Nurses repeatedly have been found to underestimate the importance of a family's needs, such as the need for information or the need to be close to the patient.^{24,31,32} These studies collectively suggest that nurses should ask a patient's family members about the members' needs rather than basing interventions on presumptions about those needs. One study³³ showed that empathy has a significant relationship with the ability to anticipate needs of patients' families and that nurses with more experience actually predicted family needs less accurately than did less experienced nurses. As these results indicate, nurses should

additional needs suggest that nurses should allow family presence as a way of helping patients' family members meet the need to provide support and safety.

The Institute of Medicine³⁵ further supports the concept of allowing family presence in an effort to improve safety and recommends that health care delivery systems become patient-centered in an effort to improve patient safety. According to the institute's patient-centered model, the patient-family dyad should be kept informed and actively involved in medical decision making and self-management. Involvement of patients' families is especially important in the ICU because patients are too ill to advocate for themselves.

For a patient-centered care model to be operationalized in the ICU, patients' family members and surrogate decision makers must become active partners in decision making and care.

France used the CCFNI in a multi-center study²⁹ and found that the satisfaction of patients' families decreased when conflicting information was received by the families and when not enough time was spent giving information, further reinforcing the importance of information and communication.

Additional studies with the CCFNI focused on the difference between needs that patients' family members thought were important and the health care providers' assessment of the members' needs. Researchers found that nurses and physicians assume what a family needs on the basis of the care providers' own

proactively ask patients' family members about the members' needs.

Burr³⁴ conducted a study to validate the CCFNI by interviewing patients' family members and comparing the members' stated needs with the needs indicated by scores on the CCFNI. Most items on the CCFNI were also disclosed during the interviews. However, family members in this Australian study reported 2 additional needs: to provide support and to protect the patient. Protecting the patient was further defined through interviews as "maintaining the vigil" or "watch[ing] over the patient" in the event that something might happen.^{34(p164)} These 2

For a patient-centered care model to be operationalized in the ICU, patients' family members and surrogate decision makers must become active partners in decision making and care.^{9,36,37} Patients' family members often have first-hand insight into patients' preferences and can make important contributions to care decisions. Research studies have not measured the effect of family presence on patients' safety. However, family members of patients may play a role in reducing medical errors by alerting staff to issues such as new changes in level of consciousness, previous response to medications, and medications taken at home.^{38,39}

The findings from Burr's study³⁴ suggest that family members want to be involved in safeguarding the patient. Logically, then, meeting the need of a patient's family members to participate, support, and protect the patient would help family members to cope with the situation. Proximity through liberal visitation will permit the safekeeping role desired by some family members.

The following real-life example occurred while I was interviewing a family in the ICU. The interview was conducted after the family members had completed the CCFNI survey. The example describes the family's need to protect the patient while showing how difficult it is for family members to adequately express their concerns without help from the nurse (J. E. Davidson, D. Agan, J. Murphy, P. Guiterrez, unpublished data, 2007). When asked, "Is there anything else I can do for you that would make this a better experience given what you've been through?" the son of an ICU patient reported an issue after being prompted by his sister. The sister was seething with anger. She demanded that he speak up. The son (brother) looked down and offered, in a measured serious voice, (paraphrased) "She has a bloody bandage on her neck. It has been there for 2 days. It is hard to look at. We only want her cared for." It appeared by the intensity of their responses that they had both been ruminating about this bandage for 2 days and that it was causing them a great deal of stress. Until then, though, they did not bring it up to the nurse. Upon inspection of the patient, it was found that it was not blood at all, but povidone-iodine on gauze covering an old central catheter insertion site.

The patient's nurse, upon hearing this, asked why the family had not asked about it before. According to Weick's organizational sensemaking theory,^{40,41} the family members' misconception had gone unchecked because they were afraid to ask about it, and reflective activity to sort through the cues in their environment had not been encouraged. These descriptions suggest that nurses, through probing questions designed to ferret out issues, concerns, misconceptions, and distortions, can prevent such events. Patients' families need to make sense of ambiguous situations, but they may not be able to do so without help.

Studies Measuring Adverse Psychological Outcomes

Anxiety

Canadian researchers^{4-6,13} have focused on the incidence of anxiety in family members of critically ill patients in relationship to whether the families' needs were met or not met according to the CCFNI. Anxiety was higher in women and was significantly influenced by family needs.¹³ The research was replicated with others in a multicenter design,⁵ and again a significant relationship was found between situational anxiety and family needs. Kloos⁴² also found high levels of anxiety in family members of ICU patients.

Anxiety, Depression, and Posttraumatic Stress Disorder

Recently, the psychological impact of critical illness on a patient's family member, particularly risk of anxiety, depression, and posttraumatic stress disorder (PTSD), has gained attention in the literature.^{2,3,11,12} The largest study to date was a multicenter

French longitudinal study.³ At 90 days after discharge or death of the patient, 33% of family members of ICU patients had moderate to high risk for PTSD. The risk increased to 80% for those family members involved in end-of-life decision making. The risk was also significantly higher in women and when not enough time was given for communication, information was incomplete, or information was not easy to understand. Pochard et al¹² also found that 73.4% and 35.3% of family members had symptoms of anxiety and depression, respectively. Because of the differences between France and the United States in culture, visiting hours, and decision-making models (paternalistic vs shared), it is not known whether these findings can be generalized to the United States.

Interventions to Meet Needs of Patients' Families or Decrease Adverse Psychological Outcomes

In contrast to the extensive studies on the needs of patients' families, relatively few studies have involved an attempt to change outcomes in patients' family members. I used MEDLINE, CINAHL, Proquest (Dissertations and Abstracts), and PsycINFO databases and the terms family and intensive care or critical care to search the literature. All the studies I found that had significant findings are reported here. The results are synthesized in the Table and scored according to the GRADE system.¹⁴

Researchers in 2 studies^{7,43} found significantly improved satisfaction among patients' families when an effort was made to improve communication. In the study by Chien et al,⁴³

Table Grading the evidence of studies with significant findings

Study	Type and size of study	Intervention	Outcome(s) of interest	Significant findings ^a
Chien et al ⁴⁴	Quasi-experimental N = 66	Structured program of education	Anxiety Satisfaction	Anxiety reduced ($P = .006$) Satisfaction increased ($P = .006$)
Medland and Ferrans ⁷	Quasi-experimental N = 30	Discussion with nurse on admission, pamphlet, daily phone call	Family's satisfaction Family's perception of met needs	Increase in satisfaction ($P < .05$) Perception of needs met increased ($P < .05$)
Melnyk et al ¹⁰	Multicenter, randomized, controlled trial (2 sites) N = 163	Video, personalized instruction, written information	Symptoms of posttraumatic stress disorder (PTSD) Depression	Symptoms of PTSD at 1 y reduced by 25% ($P < .05$), but not at earlier measuring points Depression decreased at 1 and 6 months ($P < .05$) but not at 3 months or 1 y
Lautrette et al ¹	Multicenter, randomized controlled trial (22 intensive care units) N = 126	Structured method of family conferencing plus a brochure	Symptoms of PTSD, anxiety, and depression	Symptoms significantly reduced: PTSD ($P = .01$), anxiety ($P = .02$), depression ($P = .004$)

^a Actual P value reported when available in primary source document.

^b Key for GRADE (grading of recommendations, assessment, development, and evaluation) level of evidence: high = unlikely further research would change findings, moderate = some likelihood further research may change findings, low = very likely further research may change findings, very low = evidence is not strong enough to truly estimate effect of intervention at this time.¹⁴

family members given an individualized program of information by a trained nurse whose role it was to provide education to patients' families had lower anxiety and better satisfaction than did a comparison group. In the study by Medland and Ferrans,⁷ the need for patients' family members to be called at home about changes in the patients' condition was identified from previous research in which the CCFNI was used. A 3-pronged strategy was then implemented: the ICU nurse met with each patient's family within 24 hours of the patient's admission, gave the family a pamphlet, and an ICU nurse called the family daily to

provide an update. Satisfaction and perception of information needs met were significantly higher in the experimental group. These findings support the ideas that information should be tailored to the situation and that a preformatted pamphlet may not exclusively meet the needs of all family members.

A randomized controlled trial¹⁰ of mothers and their children in a pediatric ICU indicated that a multimodal educational program to help mothers participate meaningfully at the bedside reduced PTSD symptoms at 1-year follow-up, with a trend toward reduction at earlier testing points. In that study,¹⁰ in-person instruction, a video, and written materials were given to the parents. Maternal self-reports of stress were reduced and maternal participation in care increased once the child was out of the ICU. Depression was reduced at 1 and 6

months but not at 3 months and 1 year after discharge.

Another randomized controlled trial¹ that involved bereaved family members in French adult ICUs showed that improving communication by using case conferencing plus an information leaflet decreased the risk of PTSD depression scores as well as combined anxiety and depression. Results of this cluster of studies^{1,7,10,43} further suggest that individualized, multimodal, in-person techniques to improve meeting the needs of patients' families may have a greater effect on psychological well-being of the family members than would a single intervention or a nonindividualized format. Thus, if the ICU has developed brochures for patients' family members, the brochure alone may not be enough to help family members cope with the situation. Family members need in-person assistance, communication,

dotmore

To learn more about patients' families, read "Attitudes Toward and Beliefs About Family Presence," by Christine R. Duran et al in the *American Journal of Critical Care*, 2007;16:270-279. Available at www.ajconline.org.

Country where study was conducted	GRADE level of evidence ^b	Reason for GRADE level of evidence
China	Very low	Not randomized Single site Cultural variation of care in China; findings likely to be different in the United States
United States	Very low	Not randomized Retrospective comparison group Single site Significant findings achieved with very small sample
United States	Low	Inconsistency of findings in subgroup analysis Pediatric study Findings may be different if repeated in adults Single geographic area
France	Low	Quality of study high but conducted in an environment of socialized medicine and paternalistic communication Findings likely to be different in the United States

clarification, and guidance with information tailored to their individual needs.

Conclusion

In summary, family members of ICU patients may witness a life-threatening crisis. The crisis disrupts normal life and role function.⁸ Patients' family members may not be able to act to meet the members' own needs independently at this time without assistance to sort through environmental cues and to clarify distortions and misinterpretations.⁴⁰ The response to the crisis may result in dissatisfaction, anxiety, depression, and PTSD.^{1-6,10,13,42} Nurses can assist in the compensatory process leading to adaptation through a structured approach to providing family support. Supportive actions to promote attainment of the needs of patients' families may include reflective inquiry (looking back to

clarify what has happened) and family inclusion in care.^{10,41}

Family members of ICU patients have a variety of needs (eg, proximity, information, support, assurance, and comfort) that must be fulfilled in order to support the patients through active involvement and protect the patients through maintaining a vigil.^{20,34,44} Needs are often left unmet.^{15,17,18} Fulfillment of families' needs may decrease adverse psychological outcomes, but studies to date geared toward this effort have had mixed results.^{24,42,45,46} Larger studies^{1,10} with multiple methods of intervention, at least one of which involves personal individualized interaction with a patient's family, can improve the family's outcomes.^{1,10} Therefore, individualized instruction with proactive assessment of a family's needs may help fulfill the family's needs and maximize the adaptation

of patients' family members to critical illness.

Caution is required, however, because the current level of the evidence to guide practice is very low. Although randomized controlled trials have been conducted, each trial addressed different interventions and outcomes in different settings and populations, so generalization of findings to all of critical care is not possible. Further research is indicated to validate the findings of the initial work done in this area and to test the effect of other supportive strategies on the outcomes of patients' families. **CCN**

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Financial Disclosures
None reported.

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CE Test Test ID C093: Family-Centered Care: Meeting the Needs of Patients' Families and Helping Families Adapt to Critical Illness

Learning objectives: 1. Identify 3 adverse psychological outcomes of family members of patients in ICUs 2. List the 5 categories of needs of the Critical Care Family Needs Inventory 3. Examine methods of assisting families in reflective inquiry and family inclusion in care

1. When applying Sister Calista Roy's adaptation theory to practice, the term in the model that best describes critical illness is which of the following?

- a. Disruption in life
- b. Positive adaptation
- c. Compensatory reaction
- d. Complete adaptation

2. What do the A and D stand for in the GRADE system mnemonic?

- a. Adaptation and development
- b. Assessment and disruption
- c. Adaptation and disruption
- d. Assessment and development

3. The Critical Care Family Needs Inventory includes which 5 categories of need?

- a. Support, comfort, information, proximity to patient, and assurance
- b. Communication, consistent staffing, spiritual resources, physician involvement, and unrestricted access
- c. Access to loved ones, identification of spokesperson in family, caring staff, consistent communication, and social support
- d. Patient care, guidance in treatment decisions, access to patient, knowledge of the health care provider, and assurance

4. Which of the following statements is true?

- a. Satisfaction increases when conflicting information is received by family members.
- b. Nurses and physicians accurately assume a patient's needs.
- c. Empathy has no relationship with the ability to predict a patient's needs.
- d. Nurses with more experience predicted family needs less accurately than did less experienced nurses.

5. In the study by Medland and Ferrans, what 3-pronged strategy was used to meet family needs?

- a. Family conference with physician, video about intensive care unit (ICU) care, and pamphlet
- b. Intensive care unit (ICU) nurse meets family within 24 hours, pamphlet, and daily phone calls to provide family with update
- c. ICU nurse meets family within 24 hours, video about ICU care, and family conference with physician
- d. Pamphlet, daily phone calls to provide family with update, and video about ICU care

6. What is reflective inquiry?

- a. Looking back to clarify what has happened
- b. Looking forward to determine possible future needs
- c. Questions about patient needs
- d. Questions about family needs

7. What type of study is applied in this article?

- a. Double blinded study
- b. Literature review
- c. Experimental
- d. No study reflected

8. Which of the following statements is true?

- a. In contrast to the extensive studies on the needs of patients' families, relatively few studies have involved an attempt to change outcomes in patients' family members.
- b. Databases used in the study included MEDLINE, CINAHL, and GOOGLE.
- c. Findings in France can be generalized to the United States because of the similarities in culture, visiting hours, and decision-making models.
- d. Patients' families need to make sense of ambiguous situations and do not need any help in coming to the correct conclusions.

9. Which of the following answers reflects positive adaptation to a loved one in the ICU?

- a. Depression
- b. Anger
- c. Posttraumatic stress disorder
- d. Satisfaction with care

10. Which of the following responses helps to optimize family members' experience in the ICU setting?

- a. Timely accurate and consistent communication
- b. Restricted access during the first 24 hours
- c. Increased number of attending physicians involved in care
- d. Increased number of critical care nurses involved in care

11. Which 2 areas did nurses repeatedly underestimate when dealing with a family member's needs?

- a. Need for empathy from the nurse and need to base interventions on nurses' presumptions
- b. Need for information and need to be close to the patient
- c. Need for accurate communication and need for risk assessment for posttraumatic stress disorder
- d. Need for safe care provided to loved one and need for quality time spent with physician in charge of care

Test answers: Mark only one box for your answer to each question. You may photocopy this form.

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Objective 3 was met	<input type="checkbox"/>	<input type="checkbox"/>
Content was relevant to my nursing practice	<input type="checkbox"/>	<input type="checkbox"/>
My expectations were met	<input type="checkbox"/>	<input type="checkbox"/>
This method of CE is effective for this content	<input type="checkbox"/>	<input type="checkbox"/>
The level of difficulty of this test was:		
<input type="checkbox"/> easy <input type="checkbox"/> medium <input type="checkbox"/> difficult		
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